

FINAL PROGRESS REPORT

Title of Project: Designing User-Centered Decision Support Tools for Chronic Pain in Primary Care

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Structured Abstract

Purpose: The overall objective of this study was to characterize common patterns in information availability, information use, and care planning by primary care providers (PCP) during patient visits for chronic noncancer pain (CNCP), and to use this knowledge to develop novel, guideline-based decision support tools.

Scope: Chronic pain affects an estimated 100 million Americans at a cost of \$600 billion annually. Prescription opioids have been widely prescribed for chronic noncancer pain, and contributed to opioid use disorder, overdoses, and mortality. Researchers poorly understand how clinicians interact with electronic health records to obtain information, and how clinicians use information to make sense of patients' pain diagnoses and treatments. Therefore, there is a need to describe information use and decision making in chronic noncancer pain care, and develop clinical decision support tools.

Methods: With 22 primary care clinicians, we conducted 94 interviews following an encounter with a patient with chronic musculoskeletal pain. We transcribed audio-recordings of the interviews and patient encounters, and conducted qualitative analyses to characterize information use, decision making patterns, and opportunities for clinical decision support. Next, we conducted a systems design workshop, and preliminary user testing of prototype decision support tools.

Results: The primary results of this work were general themes in primary care pain decision making, novel definitions of information needs and design seeds for chronic pain decision support, and low-fidelity prototypes of two decision support tools – Chronic Pain OneSheet and Chronic Pain Treatment Tracker.

Key Words: Chronic pain, opioids, clinical decision support, primary care

Purpose

The overall objective of this study was to characterize common patterns in information availability, information use, and care planning by primary care providers (PCP) during patient visits for chronic noncancer pain (CNCP), and to use this knowledge to develop novel, guideline-based decision support tools.

Scope

In line with the AHRQ's mission to improve the quality, safety, efficiency, and effectiveness of health care, the Agency's Health IT Portfolio aims to develop and disseminate evidence about the impact of health IT on health care quality. This project addressed the potential for IT to improve health care quality for chronic pain, an area where primary care clinicians struggle to safely and effectively treat millions of Americans. Specifically, this project was responsive to AHRQ's program announcement PA-11-198, which described an interest in studies examining "the nature of clinical expertise in individual and team decision making," "the nature of clinical work in context," and "how health care teams manage missing data or data of questionable validity or accuracy when making health care decisions."

An estimated 100 million Americans suffer from chronic pain. Moreover, pain experts question the quality of pain care and note that pain is often undertreated. Yet, pharmacies dispense more than one hundred million of opioid analgesic prescriptions yearly. Meanwhile, prescription drug abuse and opioid use disorder reached epidemic levels in the last decade, resulting in widespread morbidity and mortality.

Over the past 20 years, health care professionals have increasingly recognized a need to provide better pain care. This includes treating pain as the "fifth vital sign" that must be appropriately measured and actively managed. While progress has been made, pain diagnoses, medications, and care are poorly understood and transformative change is needed. This project contributed to this transformation by developing an in-depth understanding of how chronic noncancer pain is perceived, judged, and cared for by primary care providers. With this knowledge, we created new EHR-based decision support tools that guide clinicians' perceptions and judgments in ways that lead to increased use of guideline-based patient assessment and treatment.

The Institute of Medicine recognized a need to transform perceptions and judgments of pain because pain conditions often have complex biopsychosocial roots, and many physicians receive little formal training in caring for pain. PCPs are typically the first, and sometimes only, providers to see patients for pain, and treat approximately 52% of chronic pain patients. Furthermore, PCPs report high levels of discomfort when treating pain. Clinicians' discomfort with pain care is certainly tied to decades-long increases in opioid analgesic prescribing in recent history. This trend has contributed to widespread opioid misuse, abuse, diversion, opioid use disorder, overdoses, and mortality. Yet, research evidence on the efficacy of chronic opioid therapy is limited. Observational studies showing benefits are mostly limited to single practice settings. And, larger

epidemiologic studies have actually shown chronic opioid use to be correlated with worse pain and quality of life, suggesting that many patients do not benefit from chronic opioids. As a result, policymakers and law enforcement officials have imposed increasingly stringent regulations on opioid prescribing. The myriad challenges described above may lead some PCPs to adopt simple rules, such as “never prescribe opioids” or “refer all chronic pain cases to specialists.” However, these are not viable strategies. Millions of Americans suffer from chronic pain, and the nation has a limited supply of board-certified pain physicians. Therefore, PCPs must play a major role in chronic pain care. And, new decision support tools are needed to support PCPs in satisfactorily and effectively caring for patients with chronic pain. Together, the aforementioned factors made chronic pain care an important area for improving clinical decision support.

Methods

Study Design

We conducted a qualitative observational study that combined modified critical decision method interviews and direct observation to collect data on, and analyze, PCP’s information use and decisions when caring for CNCP. Using information systems design methods, we translated these analyses to prototype clinical decision support tools.

This project was grounded in the concept of sensemaking, and the idea that understanding clinical sensemaking would provide novel insights into the design of usable guideline-based clinical decision support. We adopted the data frame theory of sensemaking, which conceptualizes sensemaking as a dynamic process during which people iteratively seek and process data and adopt explanatory frames that help them understand events. This process is dynamic because new frames are adopted based on new information, and new information may be sought as new frames are adopted. Figure 2 provides an overview of our conceptual model, including how clinical decision support has the potential to influence clinicians’ information environments and how they respond to that environment to make decisions about assessing and treating patients.

Data Sources and Collection

Between April 2016 and July 2018, We recruited 20 PCPs who care for patients with CNCP and prescribe opioids across three health care systems spanning Indiana and Illinois. The health systems each had multiple primary care clinics. One health system was an academic safety-net provider with a network of community health centers serving an urban area in Indiana. The second health system was a not-for-profit system with primarily rural clinics in Indiana and Illinois. The third health system was a large academic system with clinics throughout Indiana in urban, rural, and suburban areas. Each recruited PCP was eligible to have 5 patient visits audio-recorded, and then participate in a follow-up interview after each visit. We transcribed and analyzed interviews as we collected data, and stopped when we determined we had reached thematic saturation. The first interview with each PCP asked about the clinicians’ patient population and general approach to CNCP, including data, tools, and instruments

commonly used. These general questions were followed by an adapted critical decision method approach in which PCPs described a recent visit by a patient with CNCP, and also discussed their history of care of that patient. Subsequent interviews used only the adapted critical decision method approach, discussing a new patient case in each interview. Probing interview questions were used to explore cues, goals, strategies, and actions taken with each patient. Questions also probed into challenging incidents that PCPs recalled in managing the patients' CNCP.

Each interview lasted approximately 45-60 minutes, and was conducted by 1-3 trained interviewers who were members of the research team. Over the course of the study, the interview guide was refined to ensure discussion of opioid-related risks, benefits, and goals (key concepts in federal opioid prescribing guidelines), and to streamline the interview process to accommodate clinician time constraints and increase process standardization.

Multiple coder analyst members of the research team conducted a series of qualitative analyses on the transcripts of the visit and interview audio. The primary analyses allowed us to characterize information use, and identify preliminary decision making requirements.

Based on the interview and visit analyses, we conducted a systems design workshop. The half-day design workshop included the research team members, and an additional five primary care physicians from outside the research team. Workshop participants worked in small groups, and, seeded by the preliminary decision requirements iteratively sketched and described visual designs of possible EHR decision support tools. The small groups presented their designs, and were video recorded. Two researchers subsequently analyzed the video recordings, notes, and drawings generated during the workshop. In the analysis, the researchers coded the content for clinical information needs and design seeds. In this study, we defined "information needs as specific clinical information elements that clinicians perceive as necessary to help assess, diagnose, and treat chronic pain" [5]. We defined "design seeds as approaches to organizing information, visually displaying information, and navigating between information elements" [5].

Interventions

This was not an interventional study. We developed prototype clinical decision support tools for chronic pain that may serve as future interventions in primary care settings.

Measures

This was a qualitative observational study that primarily used interview and observation methods. With these methods, we measured PCPs' information use and decision making patterns, and described them using narrative descriptions and direct quotes.

Limitations

This study had several limitations. First, the data collection was limited to 22 PCPs who cared for patients in only three health systems in two states. Relatedly, the study

focused on CNCP in primary care settings. Therefore, the results may not transfer or generalize beyond the types of clinicians, geography, and settings studied. Second, the study was descriptive, and used primarily self-reported measures of information use and decision making processes. Thus, descriptions of information use and decision making reflect participating clinicians' self-reports of their behavior. Finally, the study did not evaluate the effect of decision support systems on quality or health outcomes. The study concluded with prototype system development and small-scale user testing, leaving larger-scale implementation and evaluation for future work.

Results

Principal Findings

Our primary analyses examined data on 20 PCPs who participated in the interview and visit-recording component of the study. Two participants were excluded from the primary analysis because they did not prescribe or did not serve as a primary provider to patients with chronic pain. Ten were female and ten were male. 18 participants were physicians, and two were nurse practitioners. Participants' years in practice ranged from 2 to 34 years. Most PCPs participated in the maximum allowable 5 interviews, though some participated in fewer.

We identified four primary themes in chronic pain care decision making strategies used by PCPs [1]:

- 1) developing trust;
- 2) eliciting information from the patient;
- 3) diverting attention from pain to function;
- 4) articulating realistic goals for the patient.

Relatedly, we identified three themes related to PCP beliefs about opioid therapy in CNCP [1]:

- 1) opioid use tends to reduce function;
- 2) opioids are often not effective for long-term pain treatment;
- 3) response to pain and opioids is highly variable.

Additionally, we identified a series of key factors that influence a change in chronic pain treatment decisions [2]:

- 1) change in patient condition;
- 2) outcomes related to treatment;
- 3) nonadherent patient behavior;
- 4) insurance constraints;

- 5) change in guidelines, laws, or policies;
- 6) approaches to new patients;
- 7) specialist recommendations.

We also identified key aspects to include in the design of a future chronic pain decision support tool in the form of several information needs and design seeds. [5]. Key information needs that emerged as necessary to support PCP care of CNCP included:

- 1) Medication - past and current medications relevant to pain treatment and related comorbidities;
- 2) Imaging - Recent imaging (e.g., over the last 6 months) related to pain; organized by body part;
- 3) Specialty utilization - Referrals to pain-related specialists; recent specialist appointments; indication of whether referrals and appointments led to actual encounters;
- 4) Social determinants - Social factors, such as insurance status, transportation options, housing, food access, and patients' preferred language;
- 5) Outcomes and goals - current pain-related health outcomes (e.g., pain intensity, physical function, sleep disturbance) and patient-clinician goals for pain-related outcomes;
- 6) Treatment options - listing of pain treatment options (e.g., medications, physical therapy, chiropractic, transcutaneous electrical nerve stimulation, nutrition, acupuncture, mindfulness);
- 7) Context describing rationale for use and discontinuation for past treatments;
- 8) Urine drug screen results - for patients prescribed opioids, date and results of most recent urine drug screen; interpretation to identify potential medication misuse, abuse, or diversion;
- 9) Prescription drug monitoring database results - For patients prescribed opioids, date and report of controlled substances dispensed to patient; Interpretation of results to identify potential medication misuse, abuse, or diversion.

Relatedly, we identified four design seeds to guide clinical decision support systems for chronic pain care [5]:

- 1) Information accessible in a single EHR location - Pain-related information aggregated and organized in a single view in the EHR (e.g., a patient-level chronic pain dashboard).

- 2) Information organized in tables - Pain-related information organized in tables (e.g., a treatment options table or medication table).
- 3) Hierarchical information organization - Pain-related information summarized briefly with interactive capability to drill down for more details as required (e.g., clicking on a specialist appointment date to display a visit note, hovering over a physical function outcome score to display an outcome trend over time).
- 4) Visual cues to focus attention - Cues focus clinicians' attention on relevant changes, risks, or needed action (e.g., a urine drug screen result suggesting medication misuse, an overdue check of the prescription drug monitoring report, or a missed appointment for physical therapy).

Based on the information needs and decision support design seeds we identified, we developed two prototype decision support tools – Chronic Pain OneSheet and Chronic Pain Treatment Tracker.

Chronic Pain OneSheet

The Chronic Pain OneSheet was designed to provide a single accessible location in a primary care provider's EHR for gathering key clinical information and taking relevant clinical action (Figure 1). The OneSheet prototype was iteratively improved with ongoing input from the study team and clinician collaborators. OneSheet aggregates key, guideline-recommended information on one screen in the EHR, including pain-related diagnoses, opioid prescriptions (including morphine milligram equivalent dose), benzodiazepine prescriptions), patient-reported pain and function outcomes (the PEG Score), patient pain-related goals, and urine drug screen results. OneSheet also makes guideline-recommended clinical action easier and more convenient for clinicians, by including quick links to refer patients to pain-related services, to order non-opioid treatments, to review EHR-integrated prescription drug monitoring program reports, and to order common urine drug screens and confirmation laboratory tests.

Chronic Pain Treatment Tracker

Current

medication

condition

dose | quantity | frequency

take note

hydrocodone/acetaminophen (Norco)

osteoarthritis (knee/hip pain)

5/325mg #90 q6h PRN

quant. increasing, pain/function not improving

topical

referral

condition

progress

take note

physical therapy

osteoarthritis (knee/hip pain)

3 complete, 3 remaining

missed last two appointments

intervention/surgery

integrative medicine

exercise/nutrition

Past

medication

condition

date last ordered

why discontinued

ibuprofen

osteoarthritis (knee/hip pain)

6 mos ago

renal decline

pregabalin (Lyrica)

osteoarthritis (knee/hip pain)

1 yr ago

anaphylactic reaction

topical

referral

condition

date last ordered

why discontinued

orthopedic surgery

osteoarthritis (knee/hip pain)

4 yrs ago

patient declined hip replacement

intervention/surgery

integrative medicine

exercise/nutrition

Possible Future

pain clinic

orthopedic surgery

cognitive behavioral therapy

lidocaine

exercise regimen

nutrition plan

nutrition consult

diclofenac

capsaicin

duloxetine

nortriptyline

Caution

acetaminophen

NSAIDs

pregabalin (Lyrica)

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Figure 2. Chronic Pain Treatment Tracker Prototype

Discussion, Significance, and Implications

This study provides an exemplar of a user-centered design approach, in which information technology innovations were designed based on a rigorous in-depth assessment of how clinicians think and use information in day-to-day practice. The primary results of this work were general themes in primary care pain decision making, novel definitions of information needs and design seeds for chronic pain decision support, and low-fidelity prototypes of two decision support tools – Chronic Pain OneSheet and Chronic Pain Treatment Tracker. These outcomes make significant contributions to general knowledge on primary care and chronic pain care information use and decision making. These outcomes also provide a foundation for future implementation and evaluation of user-centered clinical decision support tools in primary care settings.

Beyond the scope of this grant, at the time of this writing, the Chronic Pain OneSheet was implemented as a module in the Epic EHR at two health care systems. In these two health care systems, OneSheet is being evaluated in a pragmatic randomized trial

examining whether access to OneSheet increases primary care clinicians' review and documentation of guideline-recommended clinical information for patients with chronic pain, including information on treatment risks, outcomes, and patient treatment goals. Additional outcomes include opioid prescription rates and doses, and use of risk mitigating clinical actions such as urine drug screen orders, prescription drug monitoring report review, and naloxone orders.

List of Publications and Products

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